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**Engaging use of Social Media as a research tool to capture the daily
life experiences of young people with chronic pain.**

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This article summarises a recent EBN Twitter Chat on the use of Social Media as a research tool to capture the daily life experiences of young people with chronic pain. The Twitter-Chat was led by Line Caes (@LineCaes) from the University of Stirling and Abbie Jones (@abbiejones86) a PhD student at the University of Bath. A wakelet version of the Twitter Chat can be found at: <https://bit.ly/2mJxHrx>. The pre-chat Blog can be found at: <https://bit.ly/2LKcd7m>.

Background

The current cohort of young people (between 10 and 25 years of age)⁶, is the first generation that has been born and raised in a digital environment, which profoundly affects their daily activities. These '*digital natives*', actively contribute, share, play and search social media platforms, for both academic/work and recreational purposes¹. Recent evidence demonstrates that young people spend a substantial amount of their time communicating online, with 92% of adolescents (13 – 17 years of age)⁴ going online daily and 88% of young adults (18 – 25 years of age) using any form of social media⁷. In 2015, Facebook was still the most popular social media platform amongst adolescents (used by 71%), with Instagram (used by 52%) and Snapchat (used by 41%) quickly rising in popularity. Just over 70% of adolescents also reported using more than one social networking site⁴. In contrast, a 2018 study revealed that YouTube is the most popular platform amongst young adults (used by 94%), with Snapchat and Instagram the most frequently accessed on a daily basis⁷. Approximately 80% of young adults with a Snapchat or Instagram account access these services daily, and 50-71% access their account multiple times a day⁷.

Whilst the above figures examine social media use in a general population of young people, it is anticipated that young people with a long-term condition may use social media more extensively, both in terms of time spent and platforms used. Evidence to support this idea is currently unavailable yet research has clearly demonstrated that young people experiencing chronic pain did reveal that young people typically report reduced face-to-face contact with peers due to their pain experiences⁶. Hence, to avoid isolation from their peers, these young people might rely heavily on social media to maintain their social contacts.

Currently, there is a mismatch between the heavy use of social media in young people's daily life and the standard research methods we use to understand their daily life experiences^{1,2}.

Social media data are an untapped, rich resource that could enable detailed study of young people's experiences in a way that is natural and makes sense to them. This mismatch might be due to the inability of the typically slow-paced research process⁵ not being able to keep up with the fast pace of how social media develops and changes. Indeed, using social media posts as a data collection tool is a relatively new research method with minimal guidance available. Consequently, the aim of the Twitter chat was to gain experiences of others about how to identify optimal strategies for the effective use of social media in research and pitfalls to avoid.

Key messages from the Twitter chat (#ebnjc)

1. Social Media: A critical part of young people's lives

Universally, contributors to the chat identified social media as the main channel of communication through which young people connect with likeminded peers, in addition to seeking information and support. Seemingly, keeping up with what friends are doing or posting about how individuals are feeling or on recent activities has become a key part of young people's entertainment and a way to pass time (Figure 1). Consequently, there was a common understanding amongst the participants in the Twitter chat that omitting the use of social media when conducting research with young people results in missing out on a substantial and important aspect of their daily lives.



Figure 1: Social Media: A critical part of young people's lives

2. Different platforms

Substantial discussion considered the various social media platforms available to young people, how platforms serve different functions and how young people use different platforms compared with other age groups. Social media is a broad term that involves a variety of platforms, which have different purposes ranging from building an online community (e.g. Facebook, Twitter, Snapchat), to gaming (e.g. Xbox and Playstation) and sharing knowledge on blogs and vlogs (e.g. Wikipedia, YouTube, Podcast). For research purposes, it is important to be aware of the different features of each individual platform, and how users interact with these. Researchers can then ensure that they choose a platform which not only matches their research question but is also able to answer that question in practical terms.

Related to this, discussion highlighted unanimous agreement that Instagram and Snapchat are the most commonly used platforms amongst young people and provoke most engagement from young people for research purposes. Such findings are consistent with those of the 2018 survey in young adults which identified that whilst Facebook remains the most popular platform for adults, Snapshot and Instagram are most frequently accessed amongst young adults⁷. Furthermore, it confirms the growing trend, identified in the 2015 survey⁴, of Instagram and Snapchat usage amongst adolescents and stresses the need for more up to date information on adolescents' usage of social media. Consequently, careful identification of the right platform is not only of relevance for answering the research question but also to reach and engage the target sample (Figure 2).

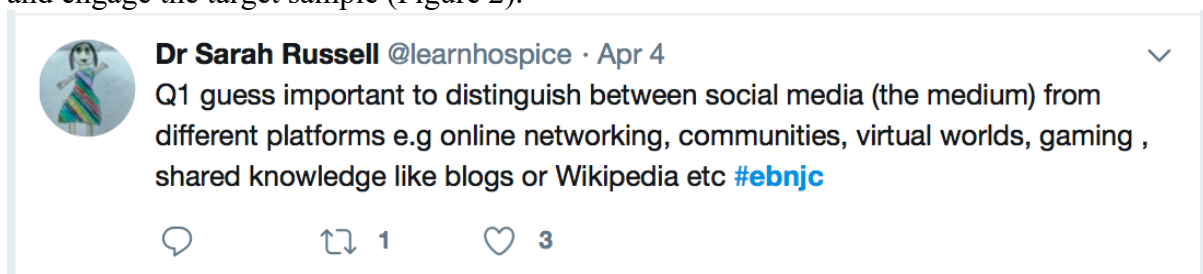




Figure 2: Different platforms with varied purposes

The Twitter chat identified that despite a plethora of social media platforms and their frequent use by young people, the study of young people's use of social media platforms has only been minimally addressed within research targeting young people with a long term condition. Only a limited amount of past and current research project using social media were highlighted, which almost solely focused on the ability to track conversations and using social media as a pain education tool. Examples of research topics using social media platforms included tracking conversations around mental health, pain in children with cancer, and benefits of social media for young people with a long-term condition (Figure 3).

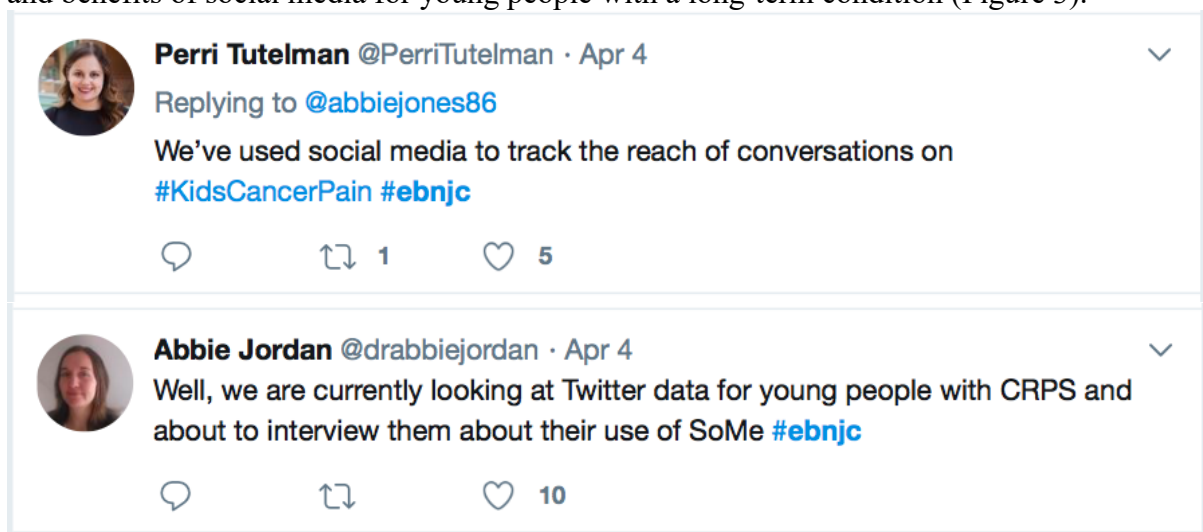


Figure 3: Social media as a tracking tool

3. Ethical and practical issues

Participants generously shared the many ethical and practical issues that had arisen in their experience of using social media as a data collection tool. One particular issue which generated considerable discussion concerned whether it is necessary to obtain consent to use social media data (and who from) given that many of the platforms are publicly available. If informed consent is required before accessing the young people's post, how do we go about obtaining informed consent? Twitter discussants agreed that we should urge young people to be cautious when engaging with unknown individuals on social media but of course, the researchers are themselves unknown to their participants at the start of the study. Questions

arose concerning how researchers can gain the trust of young people online while adhering to and supporting safety guidance. Most participants shared that they seek consent through other sources (e.g. patient organisations) before tracking the social media accounts for research purposes. Accessing young people via their parents does not seem like an effective strategy and possibly a counter-productive one (Figure 4).

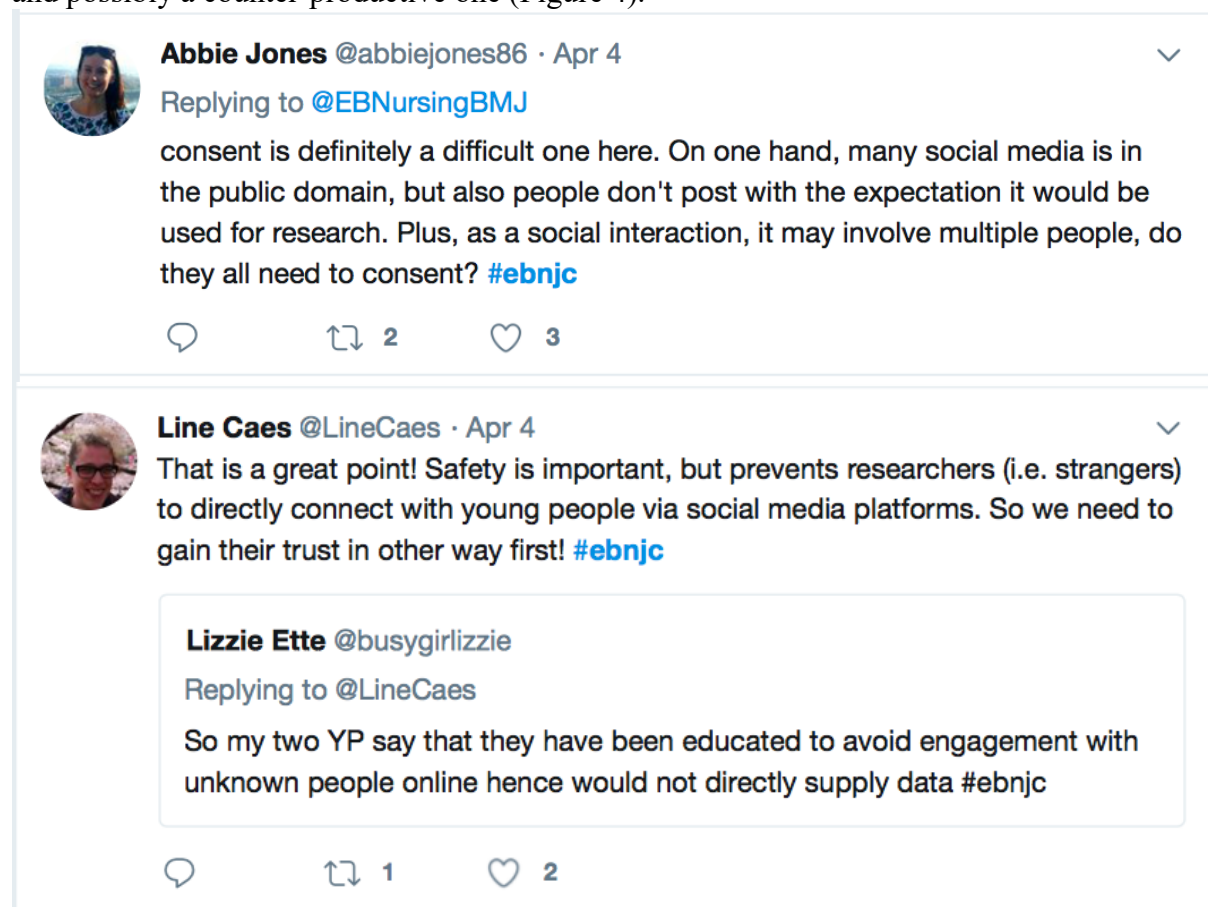


Figure 4: Questions around consent

Furthermore, it is important to keep in mind that while a large proportion of young people use social media, not all young people do. Additionally, amongst those young people who do use social media, there are substantial differences in terms of frequency of social media usage. Thinking about how this may influence use of social media as a research tool, it is possible that researchers may obtain data from a selective sample. For example, there may be a lack of representation of young people from low socio-economic status backgrounds and those are acutely ill.

An interesting point raised concerned how the challenges for using social media as a data collection tool are different depending on the specific research question to be answered and whether researchers are looking for active engagement through social media as part of the study or simply using social media as a passive tracking tool. If seeking active research contributions through social media, it is important to keep in mind that by doing this the research might be changing the young people's reality. Indeed, active engagement might require young people to make a study-specific account, only accessible to the researchers, and have them post on a subject of interest for the study. The research topic might or might not be a topic that young people have thought or posted about before. In contrast, while passive tracking might provide a more ecologically valid view of what young people

typically post about, it is important to be mindful that many of the platforms young people use (e.g. Snapchat) are more private and researchers might not have access to the full picture (Figure 5).

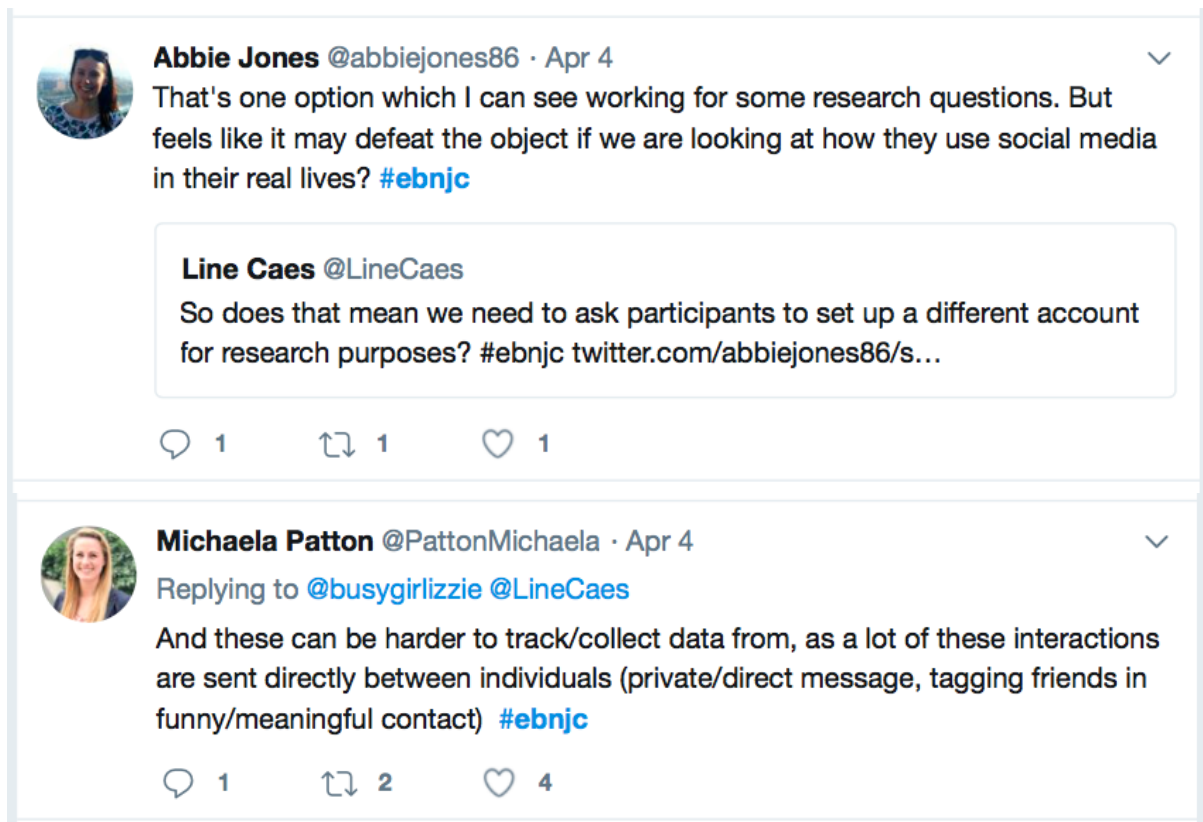


Figure 5: Challenges associated with passive and active use of social media for research purposes

Reflection on these issues and sharing resources and experience was identified as key when researchers begin to navigate this fruitful yet challenging area in their research. Participants did indeed kindly share various interesting publications on these issues and how to overcome these issues. Examples include:

- The ethics of using the internet to collect qualitative research data: <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.617.7658&rep=rep1&type=pdf>
- Social media: the relevance for research <https://ebn.bmj.com/content/19/4/99>

Conclusions

It was evident from the Twitter chat that social media includes a wide range of platforms, which are used in varied ways. Researchers need to avoid viewing social media as a single entity by being aware of these different platforms and uses. Similarly, it is important to be aware that young people are themselves a diverse group. For example, even amongst heavy users of social media, each individual's specific, personal usage of social media can look very different and serve various purposes¹. Careful consideration and selection of the right platform(s) to answer a particular research question and reach the target sample is key. Researchers must also consider the rapid technological development in the social media world. Some research findings can take up to 17 years to reach clinical practice⁵. This is particularly problematic for research involving social media use as findings may be outdated

once they reach the time point of being incorporated into practice. Consequently, research which investigates social media, and guidance for researchers on how to use social media for research needs to be substantially faster paced to ensure that it is not outdated before it is published.

Interestingly, this Twitter chat generated more questions than it could answer (Figure 6). The discussion highlighted the complexities of working with social media data to conduct research with young people, focusing on issues of consent, privacy and ecological validity. However, this is an important first step in this exciting new research direction and enthusiasm was evident from all Twitter chat participants with regard to the importance of incorporating social media in future research studies with young people. These conversations are essential for sharing good practice and ideas for how researchers can tackle the challenges posed by social media. In facilitating these types of global and interdisciplinary conversations, social media itself may provide the opportunities and resources to solve the problems that it creates.



Figure 6: More questions raised than answered.

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